

## A false sense of security

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The day Ida W. Byther-Smith learned she was HIV positive is burned into her memory. It was the same day in November 1991 that basketball great Earvin "Magic" Johnson announced his HIV status to the world.

Byther-Smith worked as a dialysis technician in a hospital and wanted to switch to a part-time position. The job change required tests for HIV and hepatitis. The tests were routine and did not faze her. She was monogamous, had never used drugs or even been accidentally stuck by a needle on the job.

When the results came back from the lab, a nurse told her she needed to speak with a doctor. Byther-Smith's heart was beating like mad as fears of cancer or tuberculosis rushed into her mind.

When the doctor broke the news, Byther-Smith thought, "You're crazy!" and insisted on a second opinion. "I thought I was the only heterosexual woman in the world not on drugs, not a prostitute, who's HIV positive," she said.

Byther-Smith took four tests in all before she would believe she was infected with HIV. She thought about drawing a warm bath and cutting her wrists.

Her distress was so intense that, having read that bleach killed the virus on syringes, she took baths with bleach in the mistaken notion it could cleanse her.

"I was trying to get it out of me before anyone found out," she said.

The most shocking news had come after her third HIV test. She found out her husband had a secret.

Byther-Smith, now 55, was married with four grown children, although she and her husband had been separated for three years. He still came by from time to time, but she hadn't slept with him during the separation.

In early 1992, the same day she got the results from her third HIV test, she got a phone call from a male friend of her husband's.

Upset and angry, she told him it was a bad time for a call, that she had just come from the doctor's office, where she had been given the same "verdict" as she had in the previous visits. Her husband's friend asked, "What did they tell you?"

She refused to tell him, so he said, "Since you won't tell me, I'll tell you. I told your husband when he and I got involved that I was infected and he told me it didn't matter. I just want you to forgive us for what we did to you."

It was then that Byther-Smith learned that her husband, Willie, who died from AIDS in 1999, was "on the down low."

"Keeping it on the down low" is a slang term for discretion in general. But the expression now commonly refers to a subculture of African-American men who lead double lives. They date or marry women but secretly have sex with men. Experts say it may explain epidemiological data that show increasing numbers of black women who aren't intravenous drug users becoming infected with HIV.

Most women who are infected with HIV by spouses experience a shattered sense of security when they learn about their mate's secret life.

Shaleyah Floyd, a clinical social worker at Cook County's Ruth M. Rothstein Core Center, said women she has counseled are engulfed by "guilt, shame and self-loathing. They say, 'I should have known better. I picked the wrong partner. What's wrong with me, that I didn't see this?'"

Gale Sergeant, a psychologist at Core, believes "only a small population we see even would admit that" their husband has sex with men.

Usually the women they feel compelled to keep two secrets--their own HIV status and their spouse's sexual orientation--from family, friends and neighbors, the therapists said.

Byther-Smith said many women just don't want to consider the possibility that their partners are on the down low or get tested for HIV.

"You look at these men, they look good, everything you'd want in a man," Byther-Smith said. "Good looking but he's still got his secret world.

"My husband was a gay basher. He would say, 'Look at those sissies ...' "

"The women feed into that. They say, 'Oh, I know he isn't gay.' But they have got to be on the watch. The men that do the most bashing are the ones patting some man's butt. That's the way I feel about it. Because a man that's secure about his masculinity is not going to put down a gay man."

Byther-Smith, a tall, warm woman with the sort of reassuring presence common among health-care workers, said it once crossed her mind that her husband might be seeing another woman. Just a feeling she had. When she brought it up, though, he denied it.

It didn't occur to her to that he could be sexually involved with men.

Once she accepted the HIV test results, Byther-Smith started working two jobs.

"I guess I was trying to work myself to death. Maybe if I worked hard enough [HIV] would leave me ... just go away. I would work all day and go home and cry. "

A religious woman, she remembered a biblical passage in which God told Nathan, a leper, to go to the Jordan River. She thought that if she could get to the Jordan River, the virus might vanish, and no one but her family would have to know. She started planning a trip to the Holy Land.

The trip got canceled and in 2000 she came down with pneumocystitis carinii pneumonia, an infection common among those with compromised immune systems, and was hospitalized with a 104-degree fever. But she wouldn't tell the doctors and nurses about her HIV status.

Doctors brought her fever down and sent her home. When she relapsed and was rehospitalized, her son insisted she tell the doctors about it. She could hardly say the words "HIV positive" to medical personnel.

When the ER nurse heard that she was HIV positive, Byther-Smith said she exclaimed "now we know what to do!"

In the nine years since learning her status, she refused to take medication and progressed to full-fledged AIDS. Doctors pumped antibiotics into her system for the pneumonia. She said she wasn't expected to live.

She pulled through, but she still refused the HIV medications.

Byther-Smith consulted her pastor, who suggested that she pray to God about the medications. She prayed, "Lord, you want me to take these meds, you better let me know."

Just three days later as she lay in her bedroom in her sunny South Shore apartment, her son, James, ushered in her case manager, who said he had come to talk about her medications. Byther-Smith thought, "God, you work really fast."

It was the sign she needed. She began a drug regimen and has adhered to it since.

Although she is managing AIDS as a chronic illness as best she can, Byther-Smith had to give up working as a dialysis technician, a job she loved. Her doctor advised her not to continue because of the risk posed for both patients and herself.

Unable to work at other jobs because of problems with concentration, she now lives on Social Security disability. Lately, along with two other "low women," partners of down-low men, Byther-Smith is trying to start a program to help HIV-positive people coming out of prison.

She speaks to church groups as often as she can, hoping to reach other women who might be living with the same false sense of security that she once had. She feels obligated.

"There is nobody else speaking out," she said. "But when I went public, all hell broke out. One of my daughters stopped speaking to me."

Rev. EartheL Fleming, of the Christ Outreach Ministries Church of God in Christ, was one of the few people to whom Byther-Smith disclosed her situation early on.

"She was very low at the beginning and didn't know what to do, like most people," Fleming said. "Now she has just blossomed--her personality, her character. Everything. She has taken up the campaign to help others."

Like many AIDS patients, Byther-Smith devotes much of her time to taking care of her health. She has no health insurance. She takes anti-retroviral medications and an antidepressant, a cholesterol-lowering drug and other medications when the need arises.

She must spend \$360 a month out of pocket for medicines and doctor visits before she can get a medical card from public aid to pay the rest of her medical needs, under the state AIDS drug assistance program.

The doctor who treats her for HIV/AIDS, she said, is able to get some medications for her through a relationship he has with a sympathetic local pharmacist.

But if Byther-Smith does not meet the \$360 "spindown" required by the state, she sometimes does without some medication.

She has tolerated the HIV/AIDS medicines well, although she experiences fatigue, so severe sometimes that she can hardly force herself out of bed in the morning.

Friends tell her she should get out and date. She doesn't want to go through the hassle of it. "You've got just as many down-low brothers sitting in church as you do on the street." Besides, she said, "I'm branded. I don't get dates, but there's more to life than dating."

Byther-Smith has learned to forgive. When her husband was homeless and dying, she took him in and nursed him.

"Holding grudges, stress, secrecy and shame kill you," she said.